



## RDLA May 2020 Newsletter

**REMINDER:** Registration for Rare Across America is now open. Register to meet with your federal legislators in August in the local and state offices at [www.RareAcrossAmerica.org](http://www.RareAcrossAmerica.org).



## CAPITOL HILL UPDATES

**COVID-19 Legislative Response:** Congress has passed four bills in the last two months to respond to the growing health and economic needs resulting from COVID-19. Most recently, Congress passed, and on April 24<sup>th</sup> the President signed into law, the Paycheck Protection Program and Health Care Enhancement Act, H.R. 266. The new law included \$310 billion for the Small Business Administrations' Paycheck Protection Program, \$75 billion for hospitals, and \$25 billion for COVID-19 testing.

On May 1<sup>st</sup>, 60 patient organizations sent a letter to the Health and Human Services' (HHS) Secretary Azar urging HHS to continue to keep the unique needs of rare disease patients and complex health conditions in mind as the country begins to plan to “reopen” in the midst of COVID-19. Specifically, the letter requests that HHS work with the patient community to consider guidelines and other policies to improve access to therapies and supportive services, the continuation of clinical trials, and the conduct of newborn screening programs. View the letter [here](#).

To learn more about the COVID-19 response passed legislation, you can listen to the April RDLA Legislative Webinar [here](#). The EveryLife Foundation also has COVID-19 related new and resources available [here](#).

**CURES 2.0:** Last month, Representatives Diana DeGette (CO) and Fred Upton (MI) shared the [CURES 2.0 Concept Paper](#) and requested feedback on questions relevant to coverage reform to

help redefine care access and delivery. The 21<sup>st</sup> Century Cures Act, signed into law on December 13, 2016, authorizes \$6.3 billion in funding to help accelerate medical product development and bring new innovations and advances to patients.

To learn more about the 21<sup>st</sup> Century Cures Act and CURES 2.0, you can listen to the March RDLA Legislative Webinar [here](#).

**Gabriella Miller Kids First Research Act 2.0, H.R. 6556:** Representative Jennifer Wexton (VA) introduced the Gabriella Miller Kids First Research Act 2.0 on April 17, 2020. H.R. 6556 proposes to provide ongoing funding for the Gabriella Miller Kids First Pediatric Research Program at the National Institutes of Health for childhood cancer and childhood disease research.



## COMMUNITY ACTION ALERTS & POLICY RESOURCES

Ear Community Organization is asking advocates to contact their Members of Congress in support of the **Ally's Act, H.R. 5485**. H.R. 5485 is a national level bill that would ensure private insurance coverage for osseointegrated hearing devices, including bone anchored hearing aids and cochlear implants, for both children and adults. To learn more about how you can support Ally's Act and ask your Representative to cosponsor H.R. 5485, click [here](#).

EveryLife Foundation for Rare Diseases is asking advocates to contact their Members of Congress to include in their FY2021 Appropriations requests increased funding for two Food and Drug Administration (FDA) programs, the Orphan Product Clinical Trial Grants Program and the Natural History Grants Program. To contact your Members, click [here](#).

Kids v. Cancer is asking organizations to sign on in support of the **Creating Hope Reauthorization Act**. The Creating Hope Reauthorization Act will permanently reauthorize FDA priority review vouchers (PRVs) for rare pediatric diseases. The PRV is a pediatric rare disease therapy development incentive program in which companies developing products for children with cancer and other life-threatening diseases may be eligible to receive a voucher from FDA that can be applied to the review for a future product that does not meet this same criteria. If your organization would like to officially support the Creating Hope Act, please sign on [here](#).

National Foundation for Ectodermal Dysplasias is asking patient advocacy organizations to sign a letter in support of the **Ensuring Lasting Smiles Act**. To sign on, visit the website [here](#). NFED is also asking advocates to send emails to their legislators to ask them to co-sponsor the Ensuring Lasting Smiles Act. Please visit [here](#).

National PKU Alliance is asking advocates to contact their Members of Congress in support of the **Medical Nutrition Equity Act, H.R. 2501**. H.R. 2501 would provide coverage of medically necessary foods and vitamins for digestive and inherited metabolic disorders under federal health

programs and private health insurance. To contact your Representative to cosponsor H.R. 2501, click [here](#).

National Society of Genetic Counselors is asking advocates to contact their Members of Congress in support of the **Access to Genetic Counselors Act, H.R. 3235**. H.R. 3235 would expand coverage of services provided by genetic counselors under the Medicare program. To contact your Representatives to cosponsor H.R. 3235, click [here](#).

Research America is asking advocates to contact their Representatives to sign onto a letter in support of **\$26 billion in COVID-19 relief to help sustain our nation's federally funded research enterprise**. To contact your Representative to sign on to the letter, click here. [Action Alert](#)

Aidan Jack Seeger Foundation is asking organizations to sign onto a letter in support of **Aidan's Law, H.R. 534**, to make newborn screenings of MPS1, Pompe, ALD, and SMA available nationwide. To view and sign on to the letter, click [here](#).

EveryLife Foundation for Rare Diseases is asking advocates to contact their Members of Congress in support of the **Advancing Access to Precision Medicine Act**. This legislation would ensure that many children and young adults living with an undiagnosed condition will have access to DNA sequencing clinical services beyond Whole Genome Sequencing that are currently out of reach. To contact your Representatives to cosponsor H.R. 4393, click [here](#).



## COMMUNITY EVENTS

*Below are upcoming policy and advocacy events of interest to the rare disease community. To view more policy and advocacy events for this year and beyond, please visit the [RDLA events calendar](#).*

**Registration is Open for Rare Across America:** Registration is now open for Rare Across America at [www.RareAcrossAmerica.org](http://www.RareAcrossAmerica.org) until July 3<sup>rd</sup>. Under the Rare Across America program, RDLA staff organizes meetings for rare disease advocates with their Members of Congress and/or the Member's staff. The meetings take place in the Member's district offices during the month of August, while Congress is in recess from August 3<sup>rd</sup> to September 7<sup>th</sup>, 2020. (Virtual meetings may take place if in-person meetings are not possible in August.)

The RDLA team prepares advocates for their meetings, provides legislative resource materials, and hosts pre-meeting training webinars. No prior advocacy experience is necessary. Save the date for the first Rare Across America training webinar for registered advocates on July 9<sup>th</sup> at 2 pm EST/11am PST and a special training on social media on July 14<sup>th</sup> at 1 pm EST/10 am PST.

**RDLA Monthly Webinar and In-Person Meeting, May 21, 2020:** The next RDLA Monthly Webinar and In-Person Meeting will take place on Thursday, May 21st. The RDLA Monthly Meetings are an opportunity to educate patient advocates about pressing health policy topics so

that they can be successful legislative advocates. The meetings are attended either through a Webinar or in person in Washington, DC. Advocates, staffers, and industry are welcome to join. Register to join on the [RDLA website](#). If you would like to present at the meeting about a current policy issue, please email Shannon von Felden at [svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org).

**RARE on the Road, a Rare Disease Leadership Tour, June 23<sup>rd</sup> and 24<sup>th</sup>:** Join the EveryLife Foundation and Global Genes on June 23<sup>rd</sup> and 24<sup>th</sup> for a virtual RARE on the Road. The two-part virtual experience that will empower attendees to build their skill set, enhance their knowledge, engage in advocacy, and network with their local rare disease community. These events are geared toward rare disease community members who want to tell their rare disease story, make an impact in the lives of others, and connect locally with fellow rare disease community members. Learn more about the virtual event at [www.raretour.org](http://www.raretour.org). Register for Part I [here](#), Part II [here](#), or both.

**Rally for Medical Research Hill Day:** Save the date for the Rally for Medical Research Hill day on Thursday, September 17, 2020, with the “Rally Hill Day” reception taking place during the evening of Wednesday, September 16, 2020. To learn more about the Rally for Medical Research, [click here](#).

### **Stay Connected**

Stay up to date on breaking rare disease legislative news by following @RareAdvocates on [Twitter](#) and [Facebook](#) and rare\_advocates on Instagram.

Receive this from a friend? [Sign-up for our email list](#) to make sure you don't miss monthly newsletters and action alerts!

\*\*\*This E-Blast shares action alerts, legislative, and policy news and events from the patient advocacy community. RDLA does not take positions on the issues herein but serves as a supportive clearinghouse for the rare disease community. Send us an email if you'd like your alerts and/or events included! Email [svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org).